Iowa Autism Council Meeting January 13, 2010

Facilitator: Sue Baker, CDD, Iowa Department of Education

<u>Present</u>: Sue Baker, Joshua Cobbs, Danielle Sharpe, Lana Michelson, Dennis Dykstra, Katherine Byers, Becky Harker, Kenda Jochimsen, Steven Muller, Jim Mumford, Mary (Grace) Percival, Dr. Jeanne Prickett, Toni Merfeld, Barbara Stineman, Patrick (Casey) Westoff, Beth Buehler (for Sonia Lewis)

<u>Absent</u>: Bill Gardam, Keith Gatrost, Pamela Parker, Dr. Charles Wadle, Dr. Debra Waldron, John Kohles

<u>Guests from Public Table:</u> Jean Nesbit, DHS – Mental Health Disability Services introduced herself to the committee; see her notes page 5

Introduction by new panel member:

Dr. Linda Louko, Director of the Wendell Johnson Speech & Hearing Clinic University of Iowa, introduced herself. She attended a monthly Asperger's support group and has a nephew with a son with autism spectrum disorder. Welcome Dr. Linda Louko.

Council Members reviewed their previously created Iowa Autism Council Recommendations as follows:

Recommendation 1 Data Tracking System

When a child enters into a support system within the educational system, an individual student identifier number is assigned for tracking purposes. The goal is to have a Longitudinal Data System developed so that data is collected beyond k-12 education, and into college at Institutes of Higher Education, Work Force Development, employment, etc.

What's in the System vs. What's missing?

The public sector information is contained within inter-system records but the private health care providers' information, Mental Health Disability information, adult services are not and therefore, this precludes having a comprehensive tracking system.

Lana reported that an exception to this sometimes occurs as follows: When a medical diagnosis is reported to a school district and becomes part of the educational record (then ruled by FERPA) the school then has access to this information. Protections via HIPPA (for example in a Court determined decision) this gap is helped through an individual being a student. However, this only happens if a diagnosis is reported to the school and becomes part of the educational record and does nothing to improve the gap situation beyond school (over 18).

Katherine Byers asked if it would be possible for Thomas Mayes at the DE to pull this court case so the council could review this and Lana said the DE could distribute documents that explain the history of this and that Sue Baker could request for Sonia Lewis to get copies of this sent out to the council.

Lana Michelson suggested that possibly Jim Addy who is the is the Chief Administrator of the DE's Division of School Support and Information Services and has been working with some federally funded grant availability for Information Technology Development Systems (Not Dept. of Education) might be able to provide this Seamless Support Subcommittee group with some very beneficial information to support their work.

Also, due to data maintained through the DE, the DE has this information for persons for 1 year beyond the end of high school due to the DE's transition needs and services records. Henceforth, for 1 year after graduation we can still access information regarding education, employment, etc. It may be even longer if the person is completing secondary education.

Josh Cobbs suggested that he and the sub-committee would do a conference call initially with Jim Addy and proceed from there with having Jim invited to an upcoming meeting if the conference call indicates that this is a lucrative idea. Lana suggested that this be done soon so the council could define what things were needed within the system.

The council was informed that on 1-12-10 (day prior to this meeting) that Post Senate Bill 30/30 passed. This bill mandates the creation of a workgroup to collaborate on best practices of technology services.

Grace Percival expressed concern that people get dropped from the educational system into their adult years.

Steven Muller mentioned that in the late 90's he recollects the attempt to creative an across the board data system so this is something that has been attempted sporadically over some period of time.

Josh Cobbs stated that he wouldn't want unilateral access by any and all agencies but the providers should have access in regards to their clients. Kenda Jochimsen told the group that with the DHS system, information is pulled out by aggregate group rather than by individual identity. Becky Harker asked about the DE's Indictor 13 and Indicator 14 statistics available through the DE and Lana confirmed that these are provided by aggregate rather than identity.

Josh Cobbs interjected that some of the AEA's systems have dropped the specific label of diagnosis on IEP's. Students are identified as being learning disabled but not with the specific diagnosis identified. Lana explained that the Secondary Designation Data Sheet must be accessed to determine the specific disability identified, i.e., Autism Spectrum disorders vs. the larger category of eligible individuals. Josh Cobbs stated that his AEA can only be accessed if written parental consent has been given.

Lana said that the DE data system has been in place for 30 years and continues to change daily. When looking at data across systems there seems to be some inconsistencies which we will be taking a closer look at in the future. As an example: only 12% of kids with Autism Spectrum Disorders are receiving speech service

Next year, Frank Forcucci, SLP Consultant (Speech and Language Pathologist) from the DE will inundate the state with high level professional development from nationally recognized services.

Sue Baker said that AEA Directors and Autism Resource Teams are getting together to look at the addressing continued staff development to increase the numbers of students being identified with the secondary disability label of ASD through IEP team data input.

Kenda Jochimsen talked about the difference between Iowa data and national data for students with disabilities. Nationally, many states besides identifying disability are also keeping residence data (i.e. living independently vs. residential living, etc.) Iowa does not do this with our disability DHS statistics.

Steven Muller stated that if you need services you need to specify what you need. Pam Alger said that when their system provides reports they include what types of services are provided and to how many but the specific identifier of diagnosis is not included.

The group determined that at least 5 different systems are being used at this time; i.e., Dept. of Human Services, Economic Development, Dept. of the Blind, Workforce Development, Dept. of Education, etc.

Steven Muller noted that sampling works great i.e., how many folks in West Des Moines are receiving services. Kenda encouraged that within the process of creation of a unilateral system that a statistician be consulted because they can provide direction on extrapolation of data and therefore how to interpret the data.

Dr. Jeanne Prickett asked if Marty Ikeda could produce a data base for this data like the one he created with the Deaf and Hard of Hearing statistics. Lana responded that a similar data base with this data could be created by Meredith MacQuigg here in the special education services bureau.

Kenda Jochimsen suggested that it would be more beneficial to put in markers rather than starting all over again, i.e., disability code, primary/secondary, ICFMR, Intermediate Care Facility for Mentally Retarded, etc. Josh Cobbs stated that we need to get back to private providers putting data into the system. Pam Alger said that within DHS it's typically a case manager who does this.

Recommendation 2 Insurance Legislation

Senate File / House File 1: This would mandate that private insurance covers public sector provided services. This requires evidence based therapies.

Advocates that have worked on getting a public hearing pushed forward on the passing of this bill.

(Congressman Warrenstad, Senator Biel, and Representative Zirkelbach)

Group did a Review of the National Standards Report published by the National Autism Center (see handout booklet)

Section 3: Overview of Rating Scale for Treatments

Section 4: pg. 43 Established Treatments

pg. 57 Emerging Treatments

pg. 70 Unestablished Treatments

There is also a section on the CLOZE reading technique.

This is available online and Sue Baker will send out to the entire council if desired, so let her know you are interested in the electronic version.

Lana also has a smaller (amended) version, entitled Findings and Conclusions, of this which she provided for anyone to take.

Recommendation 3 Improving existing waivers This group will work with DHS

Josh Cobbs – It's easier to add onto an existing waiver than to open a new one.

Grace Percival – Adding services to existing waivers is becoming a more extensive process.

Pam Alger – Due to fiscal impact executive & legislative support will be required.

Casey Westoff – Desires a reaction from key legislatures as to what support /not they would have.

Pam Alger – Finance Committee – drafting what types of services we see as needing to be put into the waivers so we need a feel for the legislative atmosphere.

Casey Westoff – We can get some work this session and place in front of the legislature, adding onto our existing recommendations.

Becky Harker – You have to be very clear about what you're asking for and have all of the content to back it up.

Sub-Committee is going to investigate putting parameters around content and finance piece.

Steve Muller – Waiver Change/Autism – existing ½ billion shortfall possibly expanding to 1 billion shortfall. Another 10% across board cut before the legislative session ends.

Grace Percival – Speech, Language & Occupational Therapy – Autism parents wants more services eligible.

Funding Streams / Service Streams

If we increase services available to Autism folks can we then tie into funding streams?

Josh Cobbs – EPIAA Funds (federal funds) Josh will send out document to group and Finance sub-committee will look into this with implications for this recommendation.

Jean Nesbit who holds a new administrative position at DHS stopped by to introduce herself to the Iowa Autism Council. She is heading up the Mental Health & Disability Services department. The council invited her to come back at another time for full meeting And she indicated she may do this after she gets settled into her new position.

Recommendation 4 Equitable Services Diagnosis to Adulthood

County Freezes on adult services – For counties with freezes in place they have no option to increase services for residents as this is overseen as a state decision. If this were decided by counties individually this could improve services for many (particularly in smaller counties).

The state CAP started in 1996 and county situations continue to decline. If the CAP were removed, counties would be able to determine distribution of services on their own. Is this possible or is a referendum or approval process necessary to initiate change?

Mental Health System Labels – Mental Illness vs. Developmental Disabilities There are groups presenting this week to the legislature their support on this issue.

Farm Bureau Insurance is against this.

Lana – Ask the legislature to look at reorganization at the county level if they choose to – legislature could tout this as a win.

Becky Harker – Suggested folks in individual counties talking to their county farm bureau folks about this issue.

Grace Percival – Could this be an action for sub-committee?

Josh Cobbs – As a council it's not our place to lobby but as individuals any actions are OK.

Steve Muller – Call your legislator and express your position regarding the county issue and ask them to give you their response regarding their stand.

Steve Muller - 0ver 2,000 people statewide are currently waiting to get on waiver eligible lists.

If a State Payment Plan is passed, 1200 folks on the State Payment Plan would have their services then being provided by private providers. For folks having no "County of Legal Settlement" providers would need to decide what they are going to do.

Recommendation 5 Stimulus Dollars to set up programs

Race to the Top (1st Round) application was just completed (1-15-10).

States with a Longitudinal Data Systems have the best chance to get in.

Requires legislative changes to lift the CAP on Charter Schools and Teacher Evaluation has to be tied to student performance.

State is required to identify the lowest achieving buildings in your state (at least 5%)

Innovation Funds Discussion

These are applied for by non DE, but are at the district level. Non-profits partnered with LEA can.

Jeanne – (correction is needed to amend the report recommendations) as it was stated the Iowa Dept. of Education is issuing these funds and that needs to be changed.

Conclusion on next steps: evaluate and put parameters around innovative programs, describing how or what they want to use them for.

Lana – She offered the services of the DE finance team when reviewing substantial information if this would be helpful to the council.

Lana – suggested possible SAMPSA Grant options

Toni Merfeld – When funds are under SED they are not disability specific.

Katherine Byers – Mentioned three priorities of scale-up grants, validation grants, and development grants.

Lana – This council would want to support a school district with plans to try to obtain innovative funds.

Specific activities from Speech Pathologist DE Consultant are being funded and include: Video Modeling

Communication with Parents

Piloting ABA Teaching Strategies using web based learning called Teach Town Basics (recently used by State of California and determined to be a "great program")

Review/update of subcommittee recommendation Early Identification by medical professionals

Proposals to support tools and training for medical professionals to diagnose (requested of Early ACCESS dollars) were not funded.

However, relating to a future subcommittee on general and special education recommendations, the follow was described:

Sue identified additional district supports including:

Increasing teams K-12 that provide social skills training to the ASD population Increasing communication and planning goals—via electronic linking of stakeholders called a Community of Practice. Two sites are being organized around state issues supporting ASD and a second site supporting goals around Early Identification & Early Intervention in ASD. Sue is organizing and these will be available on the web-site www.sharedwork.org. Sue wants the Iowa Autism Council to have representation on these sites to share information and communicate with others.

Josh Cobbs (action item) – Everyone take a look at the IAC web-site so the group can discuss at the next meeting.

Josh Cobbs will check if Jean Nesbit's new position is a replacement of Bill Gardam's; it will be investigated regarding Iowa Autism Council membership (in relation to the fact of these slots having to be governor appointed.)

Dr. Mary Larue, CHSC, IDPH will be a new member to CHSC.

ARRA funds to target improved services for Early Access providers will likely be received by CHSC:

Sue Baker explained the new STAT assessment tool, STAT – Screening Tool for Autism in Toddlers. Four staff members in each large AEA and 2 staff members in smaller AEAs will be trained using this tool to screen toddlers from 24-36 months old. This training will certify staff in this tool's use. This certified training is being provided on line through Vanderbilt University. AEA staff being certified in this tool will most likely be Autism Resource Team Members, Psychologists, or SLP's.

Review/update of subcommittee recommendation for Seamless System

The information and action items are covered above

Review/update of subcommittee recommendation for Financing Options Waivers, health insurance

There are implications of concerns amid the changes and reorganization (DHS). The chair person will continue communication with DHS to make sure the recommendations are not akin to taking a step backward.

Action regarding subcommittee work

Subcommittees already formed will continue their work as described above (Early Identification for medical providers, Insurance/Waivers, and Seamless System of Support.)

The council members present voted to choose 3 more topics to begin recommendations work from the 5 which were remaining. These five topics remaining are:

- (b) Early and Intensive Early Intervention Services
- d) General and special education support services
- e) In home support services for families requiring behavioral supports etc.
- f) Training for Educators, parents, siblings, and other family members
- g) Enhancing community agency responsiveness to adult needs and services)

They chose the following 3 items, using a priority rating type procedure. Members present volunteered for the committees. If members not present would like to volunteer their expertise and support, there are option slots on committees f) and g): If you want to volunteer on subcommittee's f and g, please e-mail Josh Cobbs by 2/15/10.

- d) general and special education support services <u>Chair name underlined</u> sub-committee members <u>Danielle</u>, Lana, Jeanne, Grace, Toni, & Josh
- f) training for educators, parents, siblings, and other family members sub-committee members <u>Sue tentative until all members are determined</u>, Linda, Josh, & Barb
- g) enhancing of community agency responsiveness to the living, learning, and employment needs of adults with autism and provision of services including but not limited to respite services, crisis intervention, employment assistance, case management, and long term care sub-committee members <u>Josh</u>, Steve, Casey, Kenda & Pam A.

Each of these sub-committees is to study and make recommendations by October 1st.

Josh will be setting up a conference call for the sub-committee chairs.

Council has to vote on the recommendations and they will then be submitted to the Governor.

Lana will check with Konni Cawiezell to verify what the Governor's response was to our last recommendations.

Josh Cobbs will call the Board Contact in the Governor's Office to get a response and extend an invitation to the board contact to report to the council at the next meeting or the following.

Tomorrow Josh Cobbs and Danielle Sharpe will go with Lana Michelson to the Joint Director's Meeting.

Toni Merfeld has ABA Booklets for the council and will distribute.

Josh Cobbs motioned to Adjourn the meeting and Casey Westoff seconded the motion.